

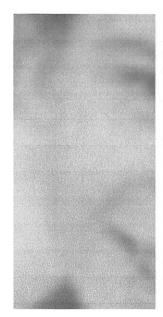
BREAKING

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## Advocates Fight for Justina Pelletier, Teen Held by State in Psych Ward

By SUSAN DONALDSON JAMES · Feb. 10, 2014













For the last year, Justina Pelletier has been in state custody in a psychiatric ward at Boston Children's Hospital.

I ay Justina Pelletier was a seemingly healthy teenager performing jumps and spirals at a skating show and six weeks later, on Feb. 10, 2013, she was in the emergency room at en's Hospital in Boston after a severe bout with the flu, refusing to eat and barely able to walk.



Her parents, Lou and Linda Pelletier of West Hartford, Conn., say their daughter was diagnosed and being treated at Tufts Medical Center for mitochondrial disease, a rare genetic disorder with physical symptoms that can affect every part of the body. Justina's sister Jessica, 25, is also being treated for the disease.

suspected the parents of child abuse for subjecting their daughter to invasive medical treatments and denying her mental health therapy.

They laid out a treatment plan for Justina, which her parents refused to sign, and on Feb. 14, 2013, when they attempted to check their daughter out of Boston Children's to take her back to Tufts to resume medical treatment, the family said they were told by Boston Children's that they could not discharge Justina.

"We never got anything in writing," said Lou Pelletier, a financial planner and father of four girls. "While all the security guards were showing up, we actually called 911 and said our daughter had been kidnapped by Boston Children's Hospital."

Pelletier said three detectives spoke to the family, then they were brought into a room and the medical team told them the hospital had contacted the DCF and under a "51A," the section of Massachusetts law that mandates health officials and others to report suspected child abuse, and "they were taking custody of our daughter."

"We didn't even get a chance to say goodbye," he told ABCNews.com.

Pelletier said his family gave its statement to the state regarding allegations of child abuse in a legally mandated hearing within 72 hours of the state taking custody, but that the court process "took until April."

For the last year, the 15-year-old has been in state custody under court-ordered treatment in a complex medical case that has pitted those involved in her care against her family and enraged advocates.

Justina was diagnosed with somatoform pain disorder, a psychiatric condition when a person experiences physical pain for which no known medical explanation can be found, according to her family. The case highlights a growing concern among those with rare diseases and autoimmune disorders that physical symptoms that cannot be explained will be dismissed by doctors as psychosomatic.

living in Framingham, Mass. They say her condition has deteriorated because the hospital has stopped all medical treatment for mitochondrial disease.

"She is going off a cliff," Pelletier said of his daughter, who is now confined to a wheelchair. "She looks awful and is pale and her hair is falling out. Her gums are receding and she has no body strength."

He said that until the gag order was in place, Justina was "sneaking notes" to the family saying that she is in permanent pain.

Justina's case made headlines last year in New England, triggering a debate over somatic illnesses — whether they are true medical issues or not and how they are treated. It also raises concerns about parental rights in choices of medical treatment and the lack of transparency in cases of alleged medical child abuse.

On Dec. 20, 2013, the court ruled the hospital should continue to retain custody, but appointed an independent investigator to take a new look at the case and a second guardian "ad litem" to legally represent the best interests of the girl, according to the Boston Globe, which did a two-part series on her case.

In the latest development, the Pelletiers have appealed to the state for custody, alleging "abuse of power." The court heard the case in January and again on Feb. 4, but postponed its decision until Feb. 13.

Because juvenile court records are confidential and Judge Joseph Johnston placed a gag order on all involved in the appeal, Justina's doctors and her caregivers have been unable to talk about the case, and it is unclear whether the teen is suffering from a physical illness or has psychiatric problems or both.

But Lou Pelletier broke his silence recently, telling ABCNews.com, "I have got to save my daughter's life."

The Massachusetts Department of Children and Families told ABCNews.com in an email that it "does not comment or provide any information regarding children in our custody," and also cited the court order.

Boston Children's Hospital said in a prepared statement to ABCNews.com that they "acknowledge the tremendous efforts of our staff in caring for this patient. We are proud of their work and positive impact on the patient."

"[O]ur clinicians are particularly distressed that the inaccuracies surrounding this case have caused undo concern for the many children and their families with mitochondrial disorders in our care," the statement added. "Misleading reports suggesting that the hospital holds patients in its inpatient psychiatric unit do not recognize the role of DCF as the legal guardian or the challenges inherent in finding appropriate lower acuity facilities for certain patients. In all cases, transfer to a less restrictive setting occurs as soon as an appropriate placement setting becomes available. Patient privacy prevents the hospital from commenting further."

Justina's ordeal began in 2010, when she had severe cramps because of a stomach blockage, according to her father. Doctors at Connecticut Children's Hospital unsuccessfully tried to "flush" her lower intestinal tract and subsequently did exploratory surgery, he said. Doctors found a congenital band, about 20 inches of cartilage wrapped around her colon and removed that and the girl's appendix, he said.

In 2011, when her condition did not improve, he said doctors referred Justina to Dr. Alejandro F. Flores, a gastroenterologist at Tufts.

In 2012, surgeons considered removing Justina's colon but eventually performed a cecostomy, attaching a device to the colon that clears the bowels of fecal matter.

Flores called in Dr. Mark Korson, chief of metabolism. Justina's sister, Jessica, had been diagnosed and continues to be a patient of Korson, according to Pelletier. Justina was

When ABCNews.com called Korson and Tufts Medical Center for comment, they declined, citing patient confidentiality. Korson and Flores are also prevented from speaking about the case because the court's gag order.

Mitochondrial disease affects the body's ability to make energy, according to Dr. Richard Boles, medical director of Courtagen Life Sciences, a genetic testing company in Massachusetts, and a practicing physician in Los Angeles.

"The symptoms can affect any part of the body," said Boles, who did not treat Justina. "It can cause just about anything. People with mitochondrial disease can have diabetes, autism or other types of retardation, seizure disorders or migraine, chronic fatigue or intestinal failure."

"People with mitochondrial disease have a lot of pain," he said. "Normal sensations are amplified by the nervous system. They are not making it up. The idea of somatoform is you are making it up to serve some need. But they are having real pain."

The disease is variable in its severity, and treatments include high doses of vitamins, antioxidants and stress reduction, according to Boles. While diagnosing the rare disease used to be controversial, doctors now have genetic tests to make clearer diagnoses.

He said he had a number of patients who had been previously diagnosed with somatoform disorder or Munchausen by proxy by "a well-meaning medical team" before he discovered they had mitochondrial disease. Munchausen by proxy is a psychiatric condition in which a caregiver, usually a parent, seeks medical attention by exaggerating, making up or even causing a child's illness.

Justina seemed to be doing well on treatments for mitochondrial disease until February 2013, when she got the flu," according to Pelletier. "When you have mitochondrial disease and get sick, it hits harder."

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She was taken by ambulance to Boston Children's on Feb. 10 and seen by a young emergency room doctor, who Pelletier alleges told the family that he "didn't believe" in mitochondrial disease. "For the first couple of days, we were open to trying a new approach," said Pelletier. But on Feb. 13, he alleges "reality started to strike."

"She had been there three days, and doctors had not had any conversation with Dr. Korson," he alleges. "They had not looked at any page of her medical records from Tufts."

On Feb. 13, Boston Children's presented the Pelletiers with a treatment plan for their daughter, which explicitly excluded input from other doctors outside its own medical team.

Since then, Korson has been an ally of the family — "one million percent," according to Pelletier, testifying in the court appeal. "He's been crying on the phone with us."

ABCnews.com obtained a copy of Justina's treatment plan, which was described as: "multidisciplinary, team based; positive, proactive, forward looking rehabilitation-center, therapeutic approach rather than diagnostic."

The plan stated that her "medication regimen will be simplified with a gradual reduction of medications to a small set of essential, non-detrimental, modestly dosed medication with limited side effects." The plan cited drugs that would continue "for now": Lyrica, which is indicated for fibromyalgia and nerve pain; and a "vitamin cocktail." But other drugs would be discontinued: Tegretol, for brain disorders and epilepsy; Milodrin, for low blood pressure; and Metoprolol, a beta blocker.

Pelletier said that when Justina was about 7, an MRI verified she had a large stroke on the left side of her brain, which affected her short-term memory. He said that withholding drugs that stabilize her heart rate could compromise her health.

He said he is "frustrated" by the hospital's allegations of over-medicalization. "Every procedure she had done was not pushed by us, but by the medical community. Insurance

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Advocates for rare diseases who say their ailments are often misdiagnosed as somatic illnesses have taken up Justina's case.

Rare diseases, a collection of about 6,800 altogether, affect an estimated 25 million to 30 million Americans, according to the National Institutes of Health. Another 23 million have difficult to diagnose autoimmune disorders.

"Every doctor, on average, may see a bare minimum of two patients a day with a rare disease. It's statistically unlikely they have seen or heard of all of them before," said Diane O'Leary, executive director of The Coalition for Diagnostic Rights, an organization that promotes the "ethical management of diagnostic uncertainty."

The Coalition says it has lodged a verbal complaint with the Massachusetts DCF for "medical child neglect and medical child abuse for failure to provide medical care" for Justina. They also argue that the state has violated an Interstate Child Placement Exchange agreement that would give Connecticut custody of Justina. They also voiced their concern to the office the Massachusetts Child Advocate office.

"Medically unexplained symptoms are automatically assumed to be psychosomatic," said O'Leary, an ethicist who for 12 years was told her own medical symptoms were psychosomatic. She was eventually diagnosed with Sneddon syndrome, a rare neurological disease.

"Doctors are absurdly reckless when they exclude a medical investigation in favor of a vague somatoform diagnosis. It's always a guess," she said. "This is a battleground where doctors and patients are fighting for authority."

Dr. Joel E. Dimsdale, professor emeritus in the psychiatry department at the University of California, San Diego, agreed that doctors must always "take symptoms very seriously," investigating all medical explanations. He chaired the committee that reviewed somatic

"The tradition of ascribing symptoms either to a physical cause or a mental cause is intellectually bankrupt," he wrote to ABCNews.com in an email. "We are not wired that way. Symptoms, regardless of their origin, cannot be processed and reported without a mental filter. We do our patients the best service by attending to both the physical and mental aspects of their symptoms."

Meanwhile, advocates for Justina say that they are not suggesting somatoform disorder be eliminated or not applied to help patients who suffer from emotional issues.

"A panic attack is a panic attack, and you don't treat it with heart drugs," said O'Leary of the Coalition for Diagnostic Rights. "But the solution is a matter of pride and humility. If a doctor is limited in his discipline, and he sees a patient with symptoms that are vague or he doesn't understand them, he should approach it with humility and the awareness that it is something he has not seen before. We are all are comfortable with a doctor who says, 'We don't know yet,' and who continues to test."

She said "it is possible" that Justina suffers from both medical problems and somatoform.



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hundred years from now there will be a nonstile approach. But at this juncture, doctors do World News Tonight World News Tonight Nighting Righting a category for symptoms they don't understand and that is indefensible." 20/20 20/20

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Intervetional David, not against Goliath, but against two Goliaths — Boston Children's Hospital Entertainment and the State of Massachusetts," Lou Pelletier told ABCNews.com. "To me it's a hopeless Hearthse and the only way to win is in the court of public opinion."

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